Disaster Research Ethics: Developing Evidence Ethically

Dónal P. O’Mathúna, PhD
School of Nursing & Human Sciences
Dublin City University, Ireland
Adjunct Assistant Professor of Emergency Medicine, The Ohio State University
Director, Center for Disaster and Humanitarian Ethics (http://www.ge2p2.org)
donal.omathuna@dcu.ie
http://disasterbioethics.eu
Definition

Disaster: ‘A serious disruption of the functioning of a community or a society at any scale due to hazardous events interacting with conditions of exposure, vulnerability and capacity, leading to one or more of the following: human, material, economic and environmental losses and impacts.’

Effect may exceed local capacity requiring external assistance.

UN Office for Disaster Risk Reduction (UNISDR): https://www.unisdr.org/we/inform/terminology
Frequency

Number of Climate-related Disasters Around the World (1980-2011)

- 3455 Floods
- 2689 Storms
- 470 Droughts
- 395 Extreme Temps
Impact

The Economic and Human Impact of Disasters* in the last 12 years

$1.3 Trillion Damage (USD)
2.7 Billion Affected
1.1 Million Killed


KEY DISASTER EVENTS
- South Asia July 2002
- Europe Aug 2002
- Bali (Indonesia) Dec 2003
- Indian Ocean Dec 2004
- Kashmir Oct 2005
- Katrina Aug 2005
- Sichuan, China May 2008
- Nargis May 2008
- Pakistan July 2010
- Haiti Dec 2010
- Japan March 2011

*Disasters refer to Natural Disasters as categorized in EM-DAT
Data source: EM-DAT, The OFDA/CRED International Disaster Database
Data versions: 10 January 2012 - v13.007
Responding

• “We don’t really know which interventions are most effective in reducing risk, saving lives and rebuilding livelihoods after crises... At present, humanitarian decisions are often based on poor information... It is extremely difficult for practitioners to access information about good practice in order to improve their own effectiveness, because information is scattered and is not available in a consistent format” (DFID, p. 5)

http://www.alnap.org/resource/9823.aspx
“much of the existing operational research related to emergencies and disasters lacks consistency, is of poor reliability and validity and is of limited use for establishing baselines, defining standards, making comparisons or tracking trends” (p. 46).


Photographs courtesy of Johan Von Schreeb
“The failure to generate and use evidence in policy and response makes humanitarian action less effective, less ethical and less accountable” (ALNAP, 2014, p. 5).

It is “unethical to deliver interventions that are, at best not proven, are ineffective or, worse still, do actual harm” (DFID, 2012, p. 11).

http://www.alnap.org/resource/10441
• “Many practitioners consider research in disaster settings to be unethical. In addition to being perceived as taking away resources from humanitarian aid, there are concerns that research can be an imposition on those already suffering, and that it does not immediately help those being studied” (DFID, 2012, p. 11).
Example: Surgery in Haiti (2010)

- Widely divergent amputation rates between surgical teams (from 1% to 45% of procedures conducted).
- Records often not kept.
- Allegations of “disaster tourism”.
- Led to retrospective studies, quantitative and qualitative.


Photo: Johan Von Schreeb
Dual Imperative
Research Ethics Frameworks

What sort of research?

• Medical interventions: randomised controlled trials (RCTs)
• “However, researchers, sponsors, research ethics committees and others must explore alternative trial designs [in disasters] that may increase trial efficiency and access to promising experimental interventions while still maintaining scientific validity. The methodological and ethical merits of alternative trial designs must be carefully assessed before these designs are used” (CIOMS Guideline 20 Commentary, 2016).
• Cluster randomised controlled trials
• Time series studies
• Outcome measurement
• Qualitative interviews
• Surveys
• Mixed methods studies
1. Collaborative partnership
2. Social value
3. Scientific validity
4. Fair selection of study population
5. Favorable risk-benefit ratio
6. Independent review
7. Informed consent
8. Respect for recruited participants and study communities

1. Collaborative Partnership

- Engage with local communities at all stages of research, from design to implementation to dissemination. Ethics does not begin with the research ethics (IRB) approval process.

- “The most appropriate decisions are likely to be made when ethical issues are thought about prior to starting research. Researchers are most likely to ‘do harm’ when they do not anticipate likely ethical challenges” (p. 13).
  

- Can be very difficult with disasters.
2. Social Value

• “The first and foremost obligation in acute disaster situations is to respond to the needs of those affected” (CIOMS, Guideline 20 Commentary).

• Responsible use of finite resources

• Starts with engagement with the local population.

• Harms are not justified if there is no social or scientific benefit.
3. Scientific Validity

- Is the study design appropriate to the research question?
- “Qualitative research is not intrinsically more ethical or of better quality; an interview can be as unethical and poorly conceived as a bad questionnaire” (p. 315).
- Is the study feasible given the disaster situation?
- Is sufficient funding available for all phases, including dissemination?
- Researcher training and support.
- “However, as is often the case in research, many of the ethical dilemmas and challenges were unexpected and faced only once the fieldwork had begun” (pp. 313).
- Post-Research Ethics Analysis (http://globalhme.org/projects/ethics/prea/)
4. Fair Subject Selection

- Participants should be chosen because of the aims of the research and its potential outcomes, not because of privilege, access, vulnerability, convenience, etc.
- Does the study need to be done in a disaster?
- Systematic review of disaster research ethics guidelines: vulnerability one of two core themes
- Are all appropriate groups included?
- Researchers “come in and just talk to the leaders and their wives—they never hear what it is really like in the camps”...; “We get no justice from the leaders, but they are the ones that UNHCR listen to” (p. 304).
5. Favorable Risk-benefit Ratio

- Risks relate to:
  - participant group
  - research methods (note psychosocial risks with qualitative research), and
  - research topic (especially social science topics).
  - AND researchers

- “If the research is determined to be of no benefit to the local population, then it should not be carried out” (p. s221).

- Principle of reciprocity and benefit sharing.

- Sets up other ethical challenges – e.g. providing direct benefits to participants and not the rest of the community.
• Humanitarian misconception: how will researchers reduce the risk of participants thinking that research participation is required to receive humanitarian aid?
6. Independent Review

- Second core theme in systematic review of disaster research ethics guidelines:
- Researchers often have real and perceived conflicts of interests.
  - Humanitarian aid worker or researcher?
  - Duty to sending agency or survivors?
  - Association with military, political, commercial, religious goals.
- Slower review versus urgent window of research ‘opportunity.’
- “Health officials and research ethics committees should develop procedures to ensure appropriate, expedient and flexible mechanisms and procedures for ethical review and oversight” (CIOMS, Guideline 20).
• “Ensure that ... the individual informed consent of participants is obtained even in a situation of duress, unless the conditions for a waiver of informed consent are met” (CIOMS, Guideline 20).

• Huge challenge: “When I go into a horrendous camp situation as a white researcher, the people are so desperate for any form of assistance they would agree to anything just on the off-chance that I might be able to assist. It makes asking for permission to interview them or take photographs a farce” (p. 234).

8. Respect for Participants and Communities

- Privacy and confidentiality must be protected.
- Participants have claimed researchers “stole our stories” (Pittaway et al., 2010).
- Requires careful engagement, e.g. Participant Action Research.
- “There is a conventional wisdom that ‘women do not talk about sexual abuse’. However, in camps and urban settings in five countries the researchers have found that by using this methodology, once trust is established and they have been involved in negotiating the process, the women are desperate to tell their stories and to share their experience’ (Mackensie et al., 2007: 314).
Beyond Codes and Guidelines

• Codes and guidelines can undercut the “sense of personal accountability and, hence, of the importance of personal integrity”

• While informed consent is important, the most reliable safeguard to ethical research involving humans is:

• “the presence of an intelligent, informed, conscientious, compassionate, responsible investigator.”
“the virtuous researcher”
- ‘a focus on the internal ethical motivation of individual investigators, not only the rules and regulations that externally motivate investigators toward compliance’ (p. 32)

https://bioethicsarchive.georgetown.edu/pcsbi/node/558.html
• Researchers and research teams need to develop the skills to:
  – identify ethical issues,
  – reflect on ethical issues,
  – reach ethical decisions that can be defended.
• AND, become virtuous researchers with the highest standards of personal and research integrity.
• Training and assessment is challenging.
• When researchers are tempted in some less than ethical direction, all they may have is their conscience and their virtues.
  – O’Mathúna DP. “The dual imperative in disaster research ethics”, in the SAGE Handbook of Qualitative Research Ethics, eds. Ron Iphofen and Martin Tolich (in press).
Further resources

- [http://DisasterBioethics.eu](http://DisasterBioethics.eu)
- [https://humanitarianhealthethics.net](https://humanitarianhealthethics.net)
- [https://BioethicsIreland.ie/disasters](https://BioethicsIreland.ie/disasters)

Thank You!